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# CANCER FACTS

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National Cancer Institute • National Institutes of Health  
Department of Health and Human Services

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## **Have a Personal or Family History of Cancer? Consider Joining the Cancer Genetics Network**

The Cancer Genetics Network (CGN) seeks individuals with a personal or family history of cancer who may be interested in participating in studies about inherited susceptibility to cancer. Nearly 8,500 individuals have enrolled in this unique program.

The Network is becoming an important vehicle to conduct studies that will provide much-needed clinical information to help individuals who may be at increased risk for cancer because of a personal or family history of the disease.

Eight U.S. centers, funded by the National Cancer Institute (NCI), joined forces 3 years ago to establish a national resource to support investigations into the genetic basis of cancer susceptibility. Together, the centers are working to make possible research that a single institution may not be able to accomplish because of insufficient numbers of participants, or the time needed to recruit them.

“The idea is to have a pool of interested individuals readily available so that important research questions can be answered, and studies can progress without unnecessary delay,” said Deborah Winn, Ph.D., acting associate director of NCI’s Epidemiology and Genetics Research Program (EGRP), Division of Cancer Control and Population Sciences (DCCPS).



Participants may be invited to be part of specific studies, depending on the research requirements, and may choose to participate on a study-by-study basis.

### **Questions in Search of Answers**

The Network's emphasis is on supporting research that brings the tremendous knowledge about genetics gained from laboratory research to bear on improving prevention, screening, diagnosis, and treatment of cancer in humans. "A wealth of new information on genetics has emerged over the past decade, and the challenge now is to find out how to make these findings meaningful in clinical practice and for public health programs," said Dr. Winn.

Some of the pressing questions that the Network aims to address are:

- How common are the genetic changes (alterations) that cause cancer in different groups?
- What determines whether someone with a genetic change gets cancer?
- What environmental exposures interact with genetic susceptibility to cause cancer?
- How can genetic discoveries be translated into better ways to prevent and treat cancer?
- What ethical, psychological, social, and family issues affect healthy individuals and their families who carry cancer susceptibility gene alterations?

"The Cancer Genetics Network is uniquely suited to support research centered on the study of key interactions between external environmental exposures and inherited susceptibility factors for cancer," said Joellen Schildkraut, Ph.D., of Duke University Medical Center, Durham, NC, and chair of the Network's Steering Committee. "This research can lead to the design of timely interventions, such as behavior modifications and chemoprevention strategies, that prevent cancer or halt its progression."

## **Being Part of the Network**

The Network offers individuals an opportunity to keep up to date on cancer genetics and potentially to participate in studies. All Network centers are enrolling eligible participants, and are especially interested in recruiting minorities, among whom membership lags. “We want all groups to be able to take advantage of this opportunity and to benefit from the studies,” said Dr. Winn.

Participants provide information about their personal and family medical histories, which is entered into a central database that is operated by an informatics group. Presently, information on more than 134,000 family members is in the database. All information is kept private and is protected by the latest communications technology safeguards.

Network researchers and their centers have longstanding experience in working with individuals and families at increased risk for cancer, and will confidentially consult with individuals who are interested in joining. “The ultimate aim is to prevent cancer, and our best hope for developing effective cancer prevention programs lies in the early identification of high-risk populations and individuals at high risk,” said Dr. Schildkraut.

## **Pilot Studies Under Way**

Although still a young program, the Network is conducting a variety of pilot studies. It also has begun to work with other research groups, and welcomes new opportunities to cooperate on important research. Some of the pilot studies under way, or slated to begin soon, are to:

- Test the value of screening for ovarian cancer among women at high risk for the disease using a blood test for CA-125 (a chemical found in the blood) and transvaginal ultrasound;
- Search for novel regions on genes associated with susceptibility to colon cancer among siblings who have a history of the disease;

- Obtain and characterize biological specimens from families who have a history of onset of prostate cancer at an early age;
- Study genetic and environmental factors that may modify risk for developing breast or ovarian cancer among women who are carriers of BRCA1 and BRCA2 gene alterations; and
- Compare statistical models for estimating the likelihood that a woman has a BRCA1 or BRCA2 gene alteration based on her family history.

## **How to Contact the Network**

Individuals may contact one of the Network centers to discuss enrollment. It is not necessary to live near a center in order to join. Some centers have hospital affiliates through which one can enroll, and much of the contact can be by telephone, mail, or e-mail. More information about the Network is available on NCI's Web site: <http://epi.grants.cancer.gov/CGN> on the Internet.

### ***Carolina-Georgia Cancer Genetics Network Center***

Institutions: Duke University Medical Center, Durham, NC, in collaboration with the University of North Carolina at Chapel Hill, NC, and Emory University, Atlanta, GA

Principal investigator: Joellen Schildkraut, Ph.D., Duke University Medical Center  
CGN Web site: <http://cancer.duke.edu/CGN>

Institution: Duke University Medical Center  
Contact: Sydnee Steadman  
Telephone: 888-681-4762 (toll free)  
E-mail: [stead006@mc.duke.edu](mailto:stead006@mc.duke.edu)

Institution: University of North Carolina at Chapel Hill  
Contact: Cindy Smith  
Telephone: 877-692-6960 (toll free)  
E-mail: [cesmith@med.unc.edu](mailto:cesmith@med.unc.edu)

Institution: Emory University  
Contact: Lisa Susswein  
Telephone: 800-366-1502 (toll free)  
E-mail: [lrs@rw.ped.emory.edu](mailto:lrs@rw.ped.emory.edu)

***Georgetown University Medical Center's Cancer Genetics Network***

Institution: Georgetown University Lombardi Cancer Center, Washington, DC  
Principal investigator: Claudine Isaacs, M.D.  
CGN Web site: <http://lombardi.georgetown.edu/research/areas/cancercontrol/cgn>  
Contact: Camille Corio  
Telephone: 202-687-8070  
E-mail: [corioc@georgetown.edu](mailto:corioc@georgetown.edu)

***Mid-Atlantic Cancer Genetics Network Center***

Institutions: Johns Hopkins University, Baltimore, MD, in collaboration with the Greater Baltimore Medical Center  
Principal investigator: Constance Griffin, M.D., Johns Hopkins University  
CGN Web site: <http://www.macgn.org>  
Contact: CGN Staff  
Telephone: 877-880-6188 (toll free)

***Northwest Cancer Genetics Network***

Institutions: Fred Hutchinson Cancer Research Center, Seattle, WA, in collaboration with the University of Washington School of Medicine, Seattle  
Principal investigator: John D. Potter, M.D., Ph.D., Fred Hutchinson Cancer Research Center  
CGN Web site: <http://www.fhcrc.org/science/phs/cgn>  
Contact: CGN Staff  
Telephone: 800-616-8347 (toll free)

***Rocky Mountain Cancer Genetics Coalition***

Institutions: University of Utah, Salt Lake City, UT, in collaboration with the University of Colorado, Aurora, CO, and University of New Mexico, Albuquerque, NM  
Principal investigator: Geraldine Mineau, Ph.D., University of Utah, Salt Lake City  
CGN Web site: <http://www.hci.utah.edu/cgn>

Institution: University of Utah  
Contact: Debra Dutson  
Telephone: 877-585-0473 (toll free)  
E-mail: [ddutson@hci.utah.edu](mailto:ddutson@hci.utah.edu)

Institution: University of New Mexico  
Contact: Lloryn Swan  
Telephone: 505-272-5659  
E-mail: swan@nmtr.unm.edu

Institution: University of Colorado  
Contact: Theresa Mickiewicz  
Telephone: 877-700-0697 (toll free)  
E-mail: theresa.mickiewicz@uchsc.edu

***Texas Cancer Genetics Consortium***

Institution: University of Texas M.D. Anderson Cancer Center, Houston, TX, in collaboration with the University of Texas Health Science Center at San Antonio, University of Texas Southwestern Medical Center at Dallas, and Baylor College of Medicine, Houston

Principal investigator: Louise C. Strong, M.D., M.D. Anderson Cancer Center  
CGN Web site: <http://texas.cgnweb.org>  
Telephone: 877-900-8894 (toll free)

Institution: Baylor College of Medicine  
Contact: Sharon Plon, M.D.  
Telephone: 713-770-4251  
E-mail: splon@bcm.tmc.edu

Institution: University of Texas Southwestern Medical Center  
Contact: Gail Tomlinson, M.D.  
Telephone: 214-648-4907  
E-mail: tomlinson@simmons.swmed.edu

Institution: University of Texas Health Sciences Center  
Contact: Susan Naylor, M.D.  
Telephone: 210-567-3842  
E-mail: naylor@uthscsa.edu

Institution: University of Texas M.D. Anderson Cancer Center  
Contact: Louise C. Strong, M.D.  
Telephone: 713-792-7555  
E-mail: lstrong@mdanderson.org

### ***UCI-UCSD Cancer Genetics Network Center***

Institutions: University of California at Irvine and University of California at San Diego  
Principal investigator: Hoda Anton-Culver, Ph.D., UC Irvine  
Contact: CGN Staff  
Telephone: 949-824-7401 (collect calls accepted)

### ***University of Pennsylvania Cancer Genetics Network***

Institution: University of Pennsylvania Cancer Center, Philadelphia, PA  
Principal investigator: Barbara Weber, M.D.  
Contact: Rhonda Kitlas  
Telephone: 888-666-6002 (toll free)  
E-mail: kitlasr@mail.med.upenn.edu

### **Informatics Infrastructure**

The CGN also has an Informatics and Information Technology Group to meet its information exchange and data management and statistical needs. The participating institutions and principal investigators are the University of California at Irvine, with Hoda Anton-Culver, Ph.D.; Massachusetts General Hospital, Boston, MA, with Dianne M. Finkelstein, Ph.D.; and Yale University, New Haven, CT, with Prakash M. Nadkarni, Ph.D.

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### **Sources of National Cancer Institute Information**

#### **Cancer Information Service**

Toll-free: 1-800-4-CANCER (1-800-422-6237)  
TTY (for deaf and hard of hearing callers): 1-800-332-8615

#### **NCI Online**

##### ***Internet***

Use <http://cancer.gov> to reach the NCI's Web site.

##### ***LiveHelp***

Cancer Information Specialists offer online assistance through the *LiveHelp* link on the NCI's Web site.

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